



All Party Parliamentary Group for Muscular Dystrophy

Access to psychological support for
people with neuromuscular conditions

November 2018

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**Muscular
Dystrophy UK**

Fighting muscle-wasting conditions



Every day counts when you're living with a muscle-wasting condition.

With over 70,000 people in the UK living with these conditions, MDUK is urgently searching for treatments and cures to improve lives today and transform those of future generations. Together, we're pressing for faster access to potential drugs and we're driving change to see better care and support to help people stay active, independent and connected.

We understand that muscular dystrophy and muscle-wasting conditions can change everything. That's why we're here for anyone who is affected, right from the moment of diagnosis and beyond. We're here to help people take back some control of their lives and to live well with the condition.

We understand the everyday challenges of muscular dystrophy and muscle-wasting conditions, so we're here with information and advice, together with emotional and practical support, a network of local groups and an online community.

www.musculardystrophyuk.org

Foreword

Access to mental health support has been an increasingly prominent issue over recent years. The importance of access to this support for people with neuromuscular conditions, as well as their families, has been evident throughout this inquiry.



We have heard many powerful and emotive testimonies from adults with muscle-wasting conditions, as well as parents of children with the condition. There is a distinct need for psychological support from the point of diagnosis onwards and at significant life milestones. The current provision does not appear to meet the need.

Health professionals and commissioners from NHS England have helped to outline guidance of good practice. They have also recommended how access can be increased and provided effectively, appropriately and efficiently.

It should also be noted that there are initiatives underway such as Muscular Dystrophy UK's Mental Health Matters campaign to educate psychologists and health professionals about neuromuscular conditions.

Whilst noting that responsibility for healthcare provision is devolved in Scotland, Wales and Northern Ireland, we have sought to align the work of this inquiry with discussions on psychological support at the muscular dystrophy cross-party groups in the Scottish Parliament, National Assembly for Wales, and Northern Ireland Assembly.

I would like to thank everyone who has contributed to this inquiry, both at the evidence sessions and in submitting evidence. This has been very informative for myself and parliamentary colleagues in the group to produce the recommendations in this report.

I hope that these recommendations will create a platform for significant improvements to access to psychological support across the country.

A handwritten signature in blue ink, appearing to read 'Mary Glendon'.

Mary Glendon

MP for North Tyneside

Chair, All Party Parliamentary

Group for Muscular Dystrophy

The All Party Parliamentary Group for Muscular Dystrophy

The All Party Parliamentary Group (APPG) for Muscular Dystrophy, chaired by Mary Glindon MP, is a group of MPs and Peers in the Houses of Parliament. Its role is to raise awareness of all types of muscle-wasting conditions and promote links between parliament, individuals and families affected by these conditions, charities and scientists, health professionals and decision-makers.

Methodology

We held three oral evidence sessions of the APPG for Muscular Dystrophy between February 2018 and May 2018. The appendix provides information on those who submitted evidence at each session. We also received written evidence from individuals and organisations with a specific interest in the inquiry's work. We are grateful to all those who assisted in our work.

Acknowledgements

Below are the Officers of the APPG and other parliamentarians who have supported the inquiry at evidence sessions:

- Mary Glindon MP (Labour, North Tyneside) (Chair)
- Rt Hon Cheryl Gillan MP (Conservative, Chesham and Amersham) (Vice Chair)
- Jim Shannon MP (DUP, Strangford) (Vice Chair)
- Baroness Thomas of Winchester (Liberal Democrat) (Vice Chair)
- Liz Twist MP (Labour, Blaydon) (Vice Chair)
- Marsha de Cordova MP (Labour, Battersea)
- Lord Kirkwood of Kirkhope (Liberal Democrat)
- Derek Thomas MP (Conservative, St Ives)

The APPG for Muscular Dystrophy wishes to thank Muscular Dystrophy UK for its administrative support in organising and staging the evidence sessions, gathering written evidence and producing a draft of this report.

This is not an official publication of the House of Commons or the House of Lords. It has not been approved by either House or its committees. All Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues. The views expressed in this report are those of the Group.

Executive summary

Immediate action is required to improve access to appropriate psychological support for people with muscular dystrophy, as well as their families.

Many people affected by these complex conditions have been struggling to access appropriate psychological support for many years. Some people have accessed counselling or generic psychological support, but, because this is not tailored towards the impact of the condition and its progression, on many occasions that generic support has not had a positive effect. This has forced many people to turn to expensive, private psychological support.

Therefore, it is clear that improvements to psychological support need to be implemented. It is also important to establish strong links with specialist neuromuscular multi-disciplinary teams to provide comprehensive co-ordinated care, which combines physical and psychological management of the condition.

As well as boosting resources, expert health professionals talked about improving the model of care. This can be explored by using comparisons from other complex long-term conditions that have more established structures of psychological support.

Plans to improve access to psychological support must include support for family members, which has been a recurrent topic of discussion throughout the inquiry. The group has heard many moving examples of the psychological impact on parents, siblings, children and grandparents, as well as the effect on family relationships.

It is evident that the lack of psychological support places an increased burden on other key neuromuscular health professionals, such as care advisors and physiotherapists. The presence of psychological support, for example within the South West Neuromuscular Operational Delivery Network, has brought significant benefit not only to the patients but also to the wider neuromuscular multi-disciplinary team.

There is also an opportunity for the NHS to explore innovative ways of providing psychological support in an appropriate way, for example using digital technology such as Skype.

The APPG for Muscular Dystrophy has identified areas for improvement, including:

- increasing clinical psychologist time dedicated to patients with muscular dystrophy
- improving the model of care to ensure that clinical psychologists are integrated and co-ordinated with specialist neuromuscular multi-disciplinary teams
- incentivising neuroscience centres listed in the Adult Specialised Neurology Service Specification to ensure psychological support is part of the provision of care
- undertaking a study of the impact on neuromuscular health professionals when dedicated psychological support is available and where it is not provided.

The APPG for Muscular Dystrophy calls on the Government, NHS England and devolved NHS bodies and administrations identified in the recommendations to take urgent action to improve the availability of appropriate psychological support for people with muscular dystrophy, as well as their families.

Recommendations

1. Only eight out of the 24 UK Muscle Centres have access to a psychologist who has training in neuromuscular conditions.¹ The APPG heard evidence that when dedicated clinical psychologist time was included in a specialist neuromuscular service there were clear benefits for the mental health and wellbeing of people with muscular dystrophy. This also alleviates the burden on other health professionals in the specialist multi-disciplinary team.

We call on NHS Trusts and NHS Boards across the UK to embed clinical psychologist time in all multi-disciplinary teams at all UK Muscle Centres. Appropriate resource should be identified to provide specialist psychological support at the Muscle Centres that currently lack such roles.

A Neurological Alliance survey (2016) found that only 19 percent of respondents rated mental health services as 'good' or 'excellent' compared to 45 percent for physical health services. This imbalance is yet to be adequately addressed.²

2. A psychologist is listed as a component part of the specialist multi-disciplinary team at a specialist neuromuscular centre in NHS England's *Neurosciences: Specialised Neurology (Adult) service specification*.³

We call on NHS England and NHS Trusts to ensure the service specification is implemented and adhered to at Neuroscience Centres by introducing incentivised initiatives.

NHS England's *Neurosciences: Specialised Neurology (Adult) service specification* states that, [following diagnosis of a neuromuscular condition], the care of all patients should be led from a regional specialist neuromuscular centre with specialist Multi Disciplinary Team (MDT) providing regular local clinics. The specialists MDT team will comprise of neuromuscular Consultants, neuromuscular physiotherapist, Neuromuscular Nurse, Occupational Therapist, Speech and Language Therapist (SALT), dietician, psychologist and neuromuscular care coordinator.⁴

3. There are lessons to be learned from pathways that have been developed for other long-term and progressive conditions, such as cystic fibrosis, diabetes and motor neurone disease, which reference the importance of psychological support at key time points.

We recommend that NHS England's Adult Neurosciences Clinical Reference Group and Paediatric Neurosciences Reference Group undertake a comparison study with other conditions to identify best practice for a model of psychological care pathway for people with muscular dystrophy, as well as family members.

1 Muscular Dystrophy UK survey of healthcare professionals on emotional support at diagnosis (2015).

2 The Neurological Alliance (2017). *Parity of esteem for people affected by neurological conditions*. 5th July. Available at: <http://www.neural.org.uk/updates/281-parity%20of%20esteem%20mental%20health>

3 NHS England (2013/4). *Neurosciences: Specialised Neurology (Adult) service specification*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2013/06/d04-neurosci-spec-neuro.pdf>

4 Bushby, K. *et al.* for the DMD Care Considerations Working Group (2010). Diagnosis and management of Duchenne muscular dystrophy, part 1: diagnosis, and pharmacological and psychosocial management. *Lancet Neurol*, 9(1), pp.77–93. Available at: [https://doi.org/10.1016/S1474-4422\(09\)70271-6](https://doi.org/10.1016/S1474-4422(09)70271-6)



Mathy Selvakumaran

Testimony from Dr Thomas-Unsworth:

“The model of identifying a mental health issue and referring on to a secondary service isn’t sufficient for neuromuscular conditions. What you see in other pathways for care with other diseases is for psychologists to get in much earlier in that process, and that whole psychological model of care allows people to respond in a timely and responsive way to the patient’s needs. I think we can identify that there are key time points in a patient’s trajectory when we know that they may have additional psychological needs: diagnosis, starting school, the transition from primary to secondary school, the transition into adult care.

“There was some very interesting mapping done by the cystic fibrosis national charity around what the tariff would look like in cystic fibrosis. They used a model, which had specific ways to track long-term health conditions over the lifetime, and used that to estimate the cost of offering a service. It was integral to how the tariff has been built for cystic fibrosis, which included psychology.”⁵

4. Support for close family members is clearly often minimal or non-existent in many parts of the UK.

We call on the UK Government and devolved administrations to produce an action plan to address how to provide psychological support for parents, siblings and other close family members with long-term and progressive conditions, and to guide and advise on the best way of supporting the family member with the condition.

⁵ National Institute for Health and Care Excellence. Cystic fibrosis pathway available at: <https://pathways.nice.org.uk/pathways/cystic-fibrosis>; MNDA pathway available at: <https://pathways.nice.org.uk/pathways/motor-neurone-disease>

Plans to improve access to psychological support must factor in support for family members; this came out as a strong and recurrent topic of discussion throughout the APPG inquiry. Many moving examples of the psychological impact on parents, siblings, children and grandparents, and the effect on family relationships, have been conveyed to the group.

Dr Hutchings commented:

“It’s really important to recognise the tension that occurs for family members who are looking after people with a long-term condition and simultaneously want them to become independent as much as they can while still wanting to look after them. Helping the parents as well as the young people through those milestones is really, really important.”

5. The clinical setting is not always the most appropriate place for psychological support, either because of the perceived negativity of the hospital environment or for geographical and travel reasons.

We recommend that NHS England provide a guidance document to identify cost-effective, appropriate opportunities for support through home visits and the use of technology. Where psychological support is provided through technology, this should be viewed as complementary to face-to-face support rather than a substitute. Psychological support should also be accessible within the community and not dependent on an individual’s attendance at clinic.

This point has been raised for other conditions, including the London Cancer Alliance: high-quality psychiatric and psychological services for those affected by cancer in the acute trust setting need to align and co-operate with services already provided through community mental health centres and primary care-based psychological treatment services. The latter have been hugely expanded over the last four years through the Improving Access to Psychological Therapies (IAPT) programme.

British Psychological Society (BPS) guidance for clinical psychologists talks about the fact that “psychologists need to ensure that services are offered in non-stigmatising, non-institutional settings in the community, including the voluntary sector, and that diversity and difference are positively valued.”⁶

The Five Year Forward View for Mental Health (2016) highlights that “Poor mental health carries an economic and social cost of £105 billion a year in England”, and that “people with long-term physical illnesses suffer more complications if they also develop mental health problems, increasing the cost of care by an average of 45%.”⁷

6 The British Psychological Society (2011). *Guidelines for Clinical Psychology Services*. July. p.8. <https://www1.bps.org.uk/system/files/Public%20files/DCP/cat-804.pdf>

7 NHS England (2016) *The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>



Sebastian Deeble

- 6. The National Institute for Health and Care Excellence (NICE) is currently developing a guideline for recognition and referral of suspected neurological conditions, which includes muscular dystrophy.**

We call on NICE to ensure that the guidelines adequately reflect the need for regular screening for mental health problems at key life-stages and access to appropriate psychological support from diagnosis onwards.

Dr Rose commented:

“Setting the bar for access to psychological services can’t only be based on anxiety and depression; it’s got to be based on the patient’s perception of their need and what their level of distress is, and we need to be smarter in measuring that. There is also an issue around the hidden parts of depression and recognising that medical services don’t reach all members of the population. My hospital has now set up a service to try and reach all patients, to at least get them screened for depression so that the scale of the problem can be recognised and the appropriate intervention delivered.”

Duchenne care guidelines say that “neuropsychological evaluations should be considered within the first year of diagnosis, to establish a baseline, or when transitioning to adulthood if government-based assistance might be necessary to promote functional independence.”⁸

⁸ Birnkrant, D.J. *et al.* for the DMD Care Considerations Working Group (2018). Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan. *Lancet Neurol*, 17(5), pp.445–455. Available at: [https://doi.org/10.1016/S1474-4422\(18\)30024-3](https://doi.org/10.1016/S1474-4422(18)30024-3)

7. The IAPT programme does not appear to be well known to many people with muscular dystrophy.

We recommend that NHS England, Clinical Commissioning Groups, charities and UK Muscle Centres explore ways of promoting IAPT and the patient experience survey to lead to improvements in psychological support. However, the provision of IAPT should not be viewed as a substitute for having clinical psychologist time embedded in multi-disciplinary teams at all UK Muscle Centres.

Muscular dystrophy is also not currently part of the coding mechanism for NHS England's IAPT services.⁹

We call on NHS England's IAPT team to work with Muscular Dystrophy UK and expert neuromuscular health professionals to develop a consistent and effective coding system.

A new IAPT service is being designed for people with long-term conditions called 'IAPT LTC'. This will aim to ensure that people with long-term conditions have the same access to NICE-recommended psychological therapies as other people have. They will bring together mental and physical health providers so they can work in a co-ordinated way to achieve the best outcomes for all people, irrespective of their diagnosis.

Around 40 percent of people with depression and anxiety disorders also have a long-term condition. Around 30 percent of people with a long-term condition also have mental health comorbidities. Currently, mental and physical health care are provided by separate services that are rarely co-ordinated. This is inconvenient for the person, costly to the NHS and likely to produce sub-optimal outcomes.

8. When there is a lack of psychological support, this can put extra pressure on other health professionals, such as neuromuscular care advisors, to fill that gap.

We recommend that NHS England undertake an impact assessment of the increased burden this places on other health professionals, and the cost-benefit to the service of increased psychologist input.

The Improving Access to Psychological Therapies (IAPT) pathway for people with long-term physical health conditions and medically unexplained symptoms: treating a person's mental health concerns saves the NHS an estimated £1,760 per person in annual expenditure on physical healthcare costs. Health professionals have estimated 57 percent of people with neuromuscular conditions would benefit from psychological support, meaning a potential saving of over £70 million to the NHS if the correct level of support were offered.

⁹ NHS England and NHS Improvement (2018) *The Improving Access to Psychological Therapies (IAPT) Pathway for People with Long-term Physical Health Conditions and Medically Unexplained Symptoms*. Available at: <https://www.england.nhs.uk/wp-content/uploads/2018/03/improving-access-to-psychological-therapies-long-term-conditions-pathway.pdf>

9. Palliative medicine for adults with neuromuscular conditions is an emerging field.

We call for this group of patients to have access to a palliative care consultant joined to a neuromuscular multi-disciplinary team. We also recommend that hospices be supported to provide palliative care for adults with neuromuscular conditions.

Prof Willis highlighted the importance of partnership working in palliative medicine:

“I would like every hospice in the country to have access to a specialist in palliative medicine. I want every patient with a neuromuscular disease, irrespective of diagnosis, to have access to someone who can give them advice. And I would also like hospitals to start working in partnership with hospices and charities, not just saying that hospices take over the role, but seriously working in partnership with hospitals to do this effectively. We’ve found that the crossover between the palliative care person and the psychologist has really helped patients to express where they wish to die. And this has prevented unnecessary hospital admissions, where people are dying in hospital when they don’t want to [die there].”

10. Newborn screening for certain neuromuscular conditions is on the horizon.

We call on NHS England to establish a newborn screening care pathway with an emphasis on named support from a clinical psychologist.

Summary of evidence

First evidence session:

Patient perspective, 21 February 2018

- Sue Barnley, whose son Harry has Duchenne muscular dystrophy
- Louisa Hill, whose son Archie has Duchenne muscular dystrophy
- Steve Ledbrook, who has Becker muscular dystrophy
- Jaspal Mann, whose son Kirath has Duchenne muscular dystrophy
- Sarah Mitchell-Innes, who has congenital myotonic dystrophy
- Mathy Selvakumaran, who has congenital myopathy

At the patient perspective session, we heard powerful testimonies from parents of children with muscular dystrophy, as well as adults with the condition. In addition, we received a large number of moving written evidence submissions. These focused on the times when they and their families needed psychological support, as well as the experiences they'd been through. These highlighted the urgency to improve access to psychological support across the country.

We heard from Sarah Mitchell-Innes about the beneficial aspect of seeing a psychologist who was knowledgeable about muscle-wasting conditions. But she had to travel from Southampton to London to access this support.

Sarah commented:

In 2016, I saw a qualified psychologist who deals with these things, and that was a real breakthrough for me because he absolutely understood what I was going through. I live in Southampton and the service is in London. I can't go there just for the psychological input; [the service] needs to be widespread throughout the country.

We were pleased to hear there was good practice to focus on and learn from.

Steve Ledbrook shared the positive impact of being able to access psychological support locally in the south west:

I couldn't work, couldn't concentrate, just everything was piling up in one go, and basically I just went to the South West Neuromuscular [Operational Delivery Network] and said I needed help. I got introduced to this psychologist, [Dr] John Ashworth, who was fantastic. He relaxed my mind and made me feel a lot better. I was able to share things because obviously there's pressure in having to sort benefits, having all these forms sent to you.

Mathy Selvakumaran highlighted the support needed at different life milestones from diagnosis onwards:

Psychological support would be really helpful throughout, from diagnosis, and especially when hitting all of those really important mental milestones – when you start going to school, start going to university. When I started going to university I had gone from having reasonable support in school to having nothing.

We were concerned to hear about the lack of appropriate support for children with muscular dystrophy, and the shortage of support available for their family members.

Louisa Hill said:

We'd seen so many people who didn't actually understand the condition themselves. I've seen counsellors privately but it doesn't just stop with Archie; it's the whole family who needs it.

Jaspal Mann also commented about the need for support and guidance for parents:

We also need support for us as parents in terms of the strategies we would need to help us help him cope with all of that anger and grief, because psychological support in a block of sessions somewhere is very limiting. It's important for continuity, to be able to keep saying the same message, and feel empowered as parents to know you're saying the right thing from a counselling perspective, that you're reinforcing that positive message as much as you can.

But also, as parents, psychological support to help us deal with that outpouring of grief and stress that we're seeing on a daily basis for quite an intense period of time and, in our case, every night. You try to remain positive and absorb all of that to make your child feel better. But at the end of the day, going out of that bedroom door, closing it, and having your own enduring grief, residual grief and distress to deal with as well, that kind of all crystallises it for you as a parent.

Support at diagnosis and in subsequent years for the family was a common theme of evidence gathered during this inquiry.

Sharon Kitcher submitted evidence about the importance of support for parents:

I received very good counselling when my son was first diagnosed. My GP referred me to the counsellor who visited the GP practice. I had a six-week session and this particular counsellor give me practical skills to cope with my situation. These skills gave me strategies to cope with many future situations and were invaluable to me. They really supported me and helped me gain confidence in dealing with my situation.

[For me] as a parent, emotions are often suppressed in order to cope on a daily basis. Our situation as parents is so unique, in that we operate in a 'mainstream' environment and secretly carry the burden of this devastating condition for a long period of time. Others, even close family and friends, struggle to offer support to us over such a long period of time.



Harry Barnley



Lizzie and Sebastian Deeble

Lizzie Deeble sent in a written evidence submission saying:

I strongly feel that this is a huge, life-changing diagnosis for a family and one in which the mental health of caregivers is very important, given the ongoing and increasing nature of the care needed. Yet psychological support is not only not offered but very difficult to access. I would very much like to see specialist counselling [...] by people with expertise and experience in this area offered to parents upon their child's diagnosis.

Anna Rogers commented in written evidence:

My two sons were diagnosed with Duchenne muscular dystrophy at the end of 2015, when Ben was eight and Sam was four. My husband and I were given the diagnosis at Addenbrooke's [Hospital] and after spending an hour with the consultant we drove the 1.5 hours home with the news that our sons had a life-limiting condition, turning our 'normal' life upside-down.

A follow-up visit with the care advisor at our home gave us the opportunity to ask questions and pour out some of our grief, after that we were, psychologically speaking, on our own. Helping those with Duchenne to come to terms with their condition and loss of function should be an integral part of helping those with muscle-wasting conditions to live a fulfilled life. Helping their families to come to terms with the fact that their child or sibling will die before them should also be a vital part of helping family carers to cope [...].



(l to r) Sue Barnley, Harry (in orange), Jack and Tom

The parent of a young man with spinal muscular atrophy (SMA) contributed to an SMA Support UK survey, sharing the challenges of providing support:

As my son has gotten older, he has a wider gap between him and his peers – he sinks low as his social group has dissipated. They attend parties, hang out, go into town and they don't invite him as he needs a carer to assist. He has also become ashamed of his body, and dislikes any attention when out and about. We have all the troubles of a teenager times 100 and we don't have the tools or vocabulary to help and we struggle too.

Sue Barnley emphasised the difficulty of knowing what to say to her son:

What I've heard every night for the last six months or so from Harry is how sad he is and the fact that he's going to be stopping walking, and 'what's the point' with some of it. Where I'm really struggling is with what to say to Harry when he tells me how sad he is.

Louisa echoed those comments and referred to the positive role played by Archie's school:

I don't feel I get enough support in knowing what to say to Archie. I feel like I'm saying the right things, but when you're broken inside and you feel as sad as you do, it's very hard to keep being positive. So I'd like to see someone be able to advise me on the right things to say to him. The best support I have had so far is in his school, in his secondary school. They've been absolutely fantastic; but they don't specialise in his condition, but they care for him and they answer his questions as best as possible. But that, to me, isn't enough. I need to see someone more professional to help me answer those questions.

Jaspal also told us about the emotional impact for her son, Kirath, highlighted from the sessions with the school counsellor:

For us, with our son, he was very young when he started showing signs of being really emotionally impacted by this. It's almost as if he had a sixth sense of what was to come within 18 months or two years because he could feel himself slowing down. At school, he became increasingly withdrawn from a lot of activities.

Luckily for him, there was a school counsellor who would take him out and have one-to-one sessions with him. She would report back to me that in those play sessions he would be picking out the toys or the figures or animals that were damaged or that didn't fit in, and he would be playing with those. But playing with them in a way that would keep them separate, or he would talk about wanting to get rid of them. Then at home he would be really angry and frustrated and he would voice how he hated his legs.

We were alarmed to hear about the lack of support available for siblings too.

Jaspal told us:

I have also felt that it would be beneficial if we were able to have good support for my older son who's not affected by this condition but who is obviously witnessing this dramatic change with his brother physically and emotionally, and struggling to come to terms with that and articulate it. He has been essentially forgotten about, and there is a huge gap that no-one seems to know about. We tried our local hospice, but their sibling support groups start at the age of 12 and our other son was younger than that when we were experiencing things at the harsh end.

Sarah talked to us about the uncertainty relating to the condition she and her daughter have:

My husband is having to deal with the thought of not knowing what's going to happen in the future. Our condition is very much, 'you just don't know'. You just don't know whether she's going to be in a wheelchair, whether I'm going to be in a wheelchair.

We learned with interest of the difference in style and approach between the UK and Canada, especially in relation to the short-term way support is provided in this country.

Mathy shared her insights:

I grew up split between Canada and here, and we found the support system in Canada a lot better. There was a hospital in Toronto that had doctors, physios, occupational therapists, and psychological support as a package from the get-go. So it meant that from diagnosis you were able to access all of those support systems. So it was a much more holistic approach to dealing with diagnosis and treatment of this condition.

What we found here, when we came here, was that a lot of problems that I was having were dealt with through primary and secondary care, using short-term solutions with paediatricians, occupational therapists, and things that would fix short-term problems. But anything else was referred to social services, who wouldn't really understand where you were coming from and you'd have to sit there and explain things to them. It kind of felt like we were being treated, in those situations outside of hospitals, as cases rather than people.

We heard that the individual with the muscle-wasting condition, or their family member, often has to take the initiative to find the support they need.

Louisa shared her thoughts:

I just feel there should be more continuity there, with the same people. I feel we should be contacted, because it's hard enough for us mums having to go through what we go through. You have to pick yourself up daily but actually having to pick up the phone or write an email to a professional having to ask for help is very, very difficult. It would be nice if someone actually came to you.

Jaspal echoed those comments:

We hear the same message, and that is that funds are getting more and more scarce, resources are decreasing at a time when demand is probably increasing, and we have experienced the same things as Louisa in terms of visits by physiotherapists and occupational therapists at home or at school. It's more of a case now of 'phone us if you need us' or else they won't really come out. It's not monitored and managed proactively. It's very reactive and it's dependent on us as parents to be completely on it all the time, to do things, to be the one to make that phone call and get somebody out.

It became clear that eventually people with muscle-wasting conditions, or their family members, feel they have to explore accessing support privately. This is often expensive, and often the only option when adequate support isn't available on the NHS.

Sue shared her experiences:

We've now found someone for Harry to talk to but it's privately. It costs £100 an hour. It isn't about the money, but it is a lot of money. We tried various people for Harry, and myself and my husband met this lady and I just knew, because when you're speaking with someone like that you've got to have a connection with them and get on with them to be able to move forward with it, and I did with her.

We tried to find someone Harry could talk to with CAMHS [Child and Adolescent Mental Health Services] and hospice and none of that worked. So we said to him, "Come and meet Michelle". Obviously, he doesn't know we pay for it or anything; I just thought he'd get on with her and he does. They get on really well together. She obviously has researched the condition; she's very up on it all. So when we meet we don't have to go through anything that we've done before. He now goes in on his own, which is what I wanted and it's brilliant.



Suzanne Glover

Mathy shared her difficulties with finding appropriate support and having to seek costly private support:

I went through generic counselling support through the university. The waiting time for them was quite long because of the amount of students that had to go through support services. I think it was a couple of months that I had to wait for an appointment. But then, they actually had to freeze the appointments because of a lack of funding. So for about a year you couldn't make an appointment. Private appointments were about £100 per hour. I had two private sessions and then I couldn't afford any more.

A parent of a child with SMA contributed to an SMA Support UK survey and shared their frustrations with trying to access the right support on the NHS and, in the end, resorting to going privately:

My GP was very sympathetic and referred me locally. This meant having an assessment on the phone by someone from local services. However, as soon as I was not deemed to be in any way 'high risk' or severely depressed, I was not able to access any one-to-one support at all. I was told to attend a local group for 'anxiety' but this was not remotely appealing or what I needed.

My apparently healthy 14-month-old child had just been diagnosed with a life-limiting condition, which meant he would never walk and would face physical challenges and vulnerabilities for the rest of his life. This meant I needed very specific support with these issues, and getting my head around what this might entail for all the parts of our lives, which would be affected. A general group discussing anxiety was never going to fit the bill for something so personal and so specific, and so I didn't get any help on the NHS. Fortunately, I was able to afford to go privately and therefore I sought out my own counsellor (at London prices), but I am very aware this is not something everyone in our position would be able to do.

'Richard' shared his testimony, which he gave to a Cross Party Group on Muscular Dystrophy meeting at the National Assembly for Wales. He commented:

I have had several sessions with a counsellor, to try and help me move away from the negatives. I have had to pay for this. Should I have to? However, it didn't really work, and I have had to resort to taking anti-depressants. This has helped a little, but I am now burdened with the shame of having to do this. I know that in some ways I am lucky. I have a fantastic wife, and I don't know how I would manage without her.

Suzanne Glover spoke about her own experiences at an All Party Group on Muscular Dystrophy meeting at the Northern Ireland Assembly:

Suddenly the effect of losing my best friend to SMA and fighting for my own life in hospital, caught up with me. My own mental health was in a pretty bad place. I spoke with my GP and she got me seen by the practice counsellor within a few weeks. I was faced with the challenge of explaining 25 years of SMA to someone who patronised me and wasn't comfortable with my mum leaving the room ... this only supported my anxieties of how vulnerable I felt. As many people have to do, I got help privately. Again, this was a challenge to find someone who could come to my house or have a wheelchair accessible practice.

So has my opinion changed? Certainly. I can now see the true value of those working in mental health to have greater understanding of the conditions. Even to have the basic understanding of the challenges SMA brings would have made my journey of mental health services a little bit easier.

Sarah emphasised that, even though the support and knowledge of other health professionals is helpful, the lack of psychological support is a significant gap:

The consultant knows about the condition; we've got a specialist nurse who knows about the condition, and knows that I've got the condition, so that's actually really nice. But it's the psychological support that we miss out on. It's great that we've got medical teams that work with us, and Hope has had all the input that she needs, and I've had all the input that I, so far, need. But it's the psychological impact of that. It's great having medical people that know about the condition, but it's the support network [that is missing].

Ellen Snead sent in evidence saying:

With my counsellor, as she didn't know anything about muscular dystrophy, it was hard to express myself for her to fully understand the feeling. But counselling did help me a bit.

Julia Coupe also commented in written evidence:

I have never received or been offered any psychological support or counselling for my neurological condition although help in this manner would have been very much appreciated at times. Families as a whole need help and guidance to cope with the ongoing changes in a neuromuscular disease. Nothing ever stays the same or can be taken for granted.

Louise Halling shared helpful insights as both a service user and a qualified, practising counsellor:

As a person living with a muscle-wasting disease myself (limb girdle muscular dystrophy), I can tell you that coming to terms with this is all about LOSS. Over time, my muscles are wasting. I am losing function. There is no treatment. I am living with pain, exhaustion and disability – disability, which is increasing with time. That is loss.

Patients living with degenerative neuromuscular conditions (or supporting those who are) are confronted daily with issues of loss: loss of identity, loss of dreams, loss of possibility, loss of function. And in some cases, the biggest loss of all: premature death. There is the loss of what a 'normal life' might have been and no longer is: a life filled with medical appointments and medication and exhaustion and trying to battle with disabled access, mobility equipment, financial constraints – as well as the bigger picture issues of genetics, life and death.

Whether as a carer or a patient, these issues are immense to come to terms with. I have no doubt at all that psychological services are necessary for people living with serious chronic illness and disability. It is simply unrealistic to assume that everyone can manage to 'go it alone'. That is a very lonely place, and often we need someone who is not in our immediate family or friendship group to come alongside us and walk with us.

We were alarmed to hear of difficulties in accessing the Child and Adolescent Mental Health Services (CAMHS), despite the urgency of support required.

Jaspal told us:

From the point of time that Kirath was referred to the CAMHS in Coventry, his first appointment was after about six to eight months; that was the lapse in time. And that was with me chasing and having a reminder in my phone every two weeks to call the local CAMHS and find out where we were in the system and how long it would be before we would hear from somebody. And that was with it being made clear on his referral form that he was low-level self-harming.

We noted that the most appropriate support wasn't always in a clinical setting.

Louisa commented about the need for support at home:

I've just had a referral from Great Ormond Street [Hospital] for Archie for an appointment, but the appointment requires going up to Great Ormond Street, which is a place Archie just doesn't enjoy going. It's somewhere that he looks at quite negatively. So, again, I'll take the referral, but it means me going up there and seeing someone with him, which he goes into with a negative mind-set straight away because he doesn't like it. As Jaspal said, you have to be going quite regularly. I would be interested to see if someone would just come to my home where Archie's most comfortable, where he would speak better.



Mathy Selvakumaran

Jaspal shared how their neuromuscular care advisor had provided some support:

We've been fortunate to have some good advice from our neuromuscular care advisor at Heartlands Hospital, although she hasn't done direct one-to-one work with Kirath. But she has, more than once, taken the time to come out to the house when Kirath's been at school and sat with us and talked about some ideas, some things we might want to try, or just listened for a while. And then said, "I'll get back to you", then followed it up with an email a few days later saying, "Okay, maybe when he's doing that don't interrupt, maybe just let him have his however long time to speak. But if you're finding that he goes on and there's not any closure happening and he needs to sleep now..."

She'll give me ideas about talking, using imagery of things he'd relate to. She's tried to give me advice that would encourage him to keep talking but also to encourage me to help guide that as well.

Sue talked about trying to implement advice for supporting her son, Harry:

But when he comes with the really hard-hitting questions, we just need some advice on what to say. In our last session there with her she said, "It's like a continuous tape playing in his head". And when he's at school sometimes he's able to be distracted, when he's on his Xbox he's distracted. But obviously, everything gets worse at night. But we've set aside, every day at 4 o'clock, me and him or his dad and him go to our room, not to be disturbed, with low lighting, not looking at each other, and we see if he'll start to talk. We're quite early days with it, and he's a bit like, "This is rubbish", but then I'll try and prompt a few things. The idea is trying to get him to offload earlier on, 4-ish, and that's our 'worry time', so we can talk about it, and so that will hopefully make bedtime a bit better.

We were keen to find out how the panel members planned for their futures.

Mathy shared her concerns with us:

I'm 28 now and I need to start thinking about my future proactively myself. And for me, that's really daunting, because no-one's really explained to me what happens after you're 18 and what care you need to look at for yourself.

So for me, I think I'm struggling because I can't rely on my mum to do things for me forever. I'm at the point where I need to look for that support but I don't know where to go, and I think that's the problem.

Once you turn 18, and once you leave paediatric services, you lose that regular medical support. It's hard to get back into it beyond primary care, ICU, and physiotherapists. It's hard for me and that's what I'm worried about. It's hard to access that medical support but then also to access that psychological support alongside that.

Sue commented on the difficulty of planning ahead:

I think it feels so bad at the moment. You hear time and time again, once they're past the age of 18, it seems to sort of go off a cliff and you think, "Where are you? Who's looking after you?" So at the moment, we feel like we're firefighting. You have to do it on your own. So, no, I can't see the future being any better.

We opened up the session to the audience to gather additional views and experiences.

Phillippa Farrant, whose son, Dan, has Duchenne muscular dystrophy, told us:

In the last year when I've had to sign DNRs [Do Not Resuscitate], I've had no psychological back-up. I need to talk to someone about the fact that the next time my son goes into hospital he might not come out. I've had no support for that at all. I'm quite a strong person, the other mums here know me as a strong person, but there are times when I need that psychological support.

Shelley Simmonds, whose son Fraser has Duchenne muscular dystrophy, said:

I don't know if maybe I'm not offered that psychological support because I come across as strong, but you don't know what goes on in someone's mind, behind closed doors. Just because I'm not often tearful and generally try and be positive for my son, doesn't mean I'm not crying out for that support. I'm never asked if I'm okay.



Harry Barnley



Steve Ledbrook

Sharon Ledbrook, whose son Steve also gave evidence, commented:

It is a hard and often lonely road to take when you have a child with a disability, because that's never going to change. It's ongoing. And in 20 years' time, you wonder what happens to them, will they have that support? We don't know. I think it's important that we can move forward somehow and get that emotional support. The welfare of not only our children, but [of] us as mothers is important.

Andrew Robertson, who has limb girdle muscular dystrophy, shared his thoughts about talking to his young son:

For me, it's also the impact it's had on my four-year-old. He's always seen me in a wheelchair, but I try and think about how it's going to affect him as he's growing up. I listen to him sometimes talking with the carer, and he says, "One day my dad will be better, he'll be able to do things", and I wonder where that comes from. Whether it's something I've said, but I have no experience of how to deal with that with a four-year-old.

Second evidence session: Health professional perspective, 21 March 2018

- Dr Caroline Hutchings, Consultant in Rehabilitation Medicine
 - Dr Andria Merrison, Consultant Neurologist
 - Dr Jatin Pattni, Specialist Clinical Psychologist
 - Dr Michael Rose, Consultant Neurologist
 - Andrea Russell, Neuromuscular Care Advisor
 - Dr Sadie Thomas-Unsworth, Specialist Clinical Psychologist
 - Professor Derek Willis, Consultant in Palliative Medicine
 - Dr Ingram Wright, Consultant Paediatric Neuropsychologist
-

Health professionals gave us helpful and informative evidence to establish the level of current provision and gather examples of good practice. They also made suggestions of how to improve the model of care provision and infrastructure of psychological support.

We heard from Dr Merrison about provision in the south west of England:

We are probably one of the only places in the country, in the South West Neuromuscular [Operational Delivery] Network, where there is dedicated psychological support, which was secured through specialised commissioning.

However, across many parts of the country, finding the appropriate psychological support for these conditions is clearly extremely challenging.

Dr Pattni described the difficulties for patients in accessing suitable psychological support:

The challenge is that there are services out there in the community but it's difficult for our patients to actually access them because they're unsuitable for neuromuscular conditions. General mental health services don't offer the skills or expertise to treat patients with neuromuscular conditions.

Dr Rose also shared the challenges:

Patients with muscle-wasting conditions are either too complex for the widely available psychiatric services, or else they don't fall into the condition-specific categories that would qualify for the more hospital-based psychiatric services.

Andrea Russell outlined the difficulties in getting psychological support in the east of England region:

We have been in community services where we've felt people have fallen through the gap. We have put through individual requests for funding for psychology groups, and where we've been able to identify an urgent need we've had limited success.

Dr Wright shared his views of the Child and Adolescent Mental Health Services (CAMHS):

My experience in referring to CAMHS, and this applies across the range of conditions, is that it's extraordinarily difficult to get access to CAMHS services if you already have a neurological condition. Any patient who doesn't meet a very high threshold of need would have a lot of difficulty accessing mental health services given the poor state of resources. The bar is set increasingly high in terms of access requirements for those services. I think if you've got someone with a neurological condition, there's even more of a barrier that prevents access.

Dr Pattni also highlighted the extent of anxiety and depression:

If you start asking, you realise just how prevalent these anxiety and depression cases are among neuromuscular patients. The challenge is, once they get past the physical health issues, actually living with and learning how to live with a condition that has a profound effect on their life.

We were concerned to hear that muscular dystrophy pathways lagged behind other condition pathways, without a clear model of care.

Dr Thomas-Unsworth commented:

The model of identifying a mental health issue and referring on to a secondary service isn't sufficient for neuromuscular conditions. What you see in other pathways for care with other diseases is for psychologists to get in much earlier in that process, and that whole psychological model of care allows people to respond in a timely and responsive way to the patient's needs.

I think we can identify that there are key time points in a patient's trajectory when we know that they may have additional psychological needs: diagnosis, starting school, the transition from primary to secondary school, the transition into adult care.

There was some very interesting mapping done by the cystic fibrosis national charity around what the tariff would look like in cystic fibrosis. They used a model, which had specific ways to track long-term health conditions over the lifetime, and used that to estimate the cost of offering a service. It was integral to how the tariff had been built for cystic fibrosis, which included psychology.



Fraser Simmonds

Dr Rose described the improvements that need to occur when a diagnosis is given to someone with muscular dystrophy:

I think we could learn from the model used for motor neurone disease. We could set similar standards for how neuromuscular conditions could be psychologically supported. One of the common themes we hear, speaking with patients, is that they first hear nothing is wrong with them, then they receive the wrong diagnosis, then finally they're given a diagnosis and told it's going to get worse. That sort of approach has to be countered by clear, accepted standards of how diagnosis should be given. Not just giving a diagnosis with no follow-up of what happens afterwards.

We acknowledged just how many people, who access neuromuscular services, needed support.

Dr Merrison emphasised the importance of integrating care:

Everybody should have equitable access at the point of need, and the only way of achieving that is to have psychological services integrated into your healthcare provision so that it is there at the point at which a patient interacts with your service and is there throughout their journey. I'd say about 40 percent of patients who I've seen over the last three or four years have accessed these types of service for either themselves or their family members.



Suzanne Glover

We were encouraged to hear from Dr Rose that there were proactive steps being taken to assess the need for psychological support:

Setting the bar for access to psychological services can't only be based on anxiety and depression. It's got to be based on the patient's perception of their need and what their level of distress is, and we need to be smarter in measuring that. There is also an issue around the hidden parts of depression and recognising that medical services don't reach all members of the population. My hospital has now set up a service to try and reach all patients, to at least get them screened for depression so that the scale of the problem can be recognised and the appropriate intervention delivered.

When we were devising the clinical trial I'm involved with [Acceptance and Commitment Therapy for Muscle Disease (ACTMus)], we purposely created self-help intervention with a series of online modules, each one of which is supported with a telephone call from the psychologist. That was in recognition of the fact that we wanted to test an intervention, which would be general and then be taken out of a clinical trial setting and delivered nationally to meet the geographical spread of the population involved, and with the lack of psychologists to deliver support in a clinical outpatient setting.

We were also keen to explore the alternative settings, which were repeatedly highlighted by the patient and family perspectives. Dr Hutchings commented:

Our transition therapy team like to add a third venue, which is 'where my mother isn't' and 'not in your hospital'. So our staff often meet people in Ikea, for example, as well as other public places. They have a great knowledge of which shops have got secluded booths so they can have private conversations publicly, where the patient's 'mother isn't'. Young people report that the opportunity to see OTs [occupational therapists] 'somewhere normal' is really important.

Prof Willis commented on the value of a home visit:

When someone comes to my hospital or my clinic, that's where I have control, and people often won't tell me what's going on because you have to 'behave' at the doctor's clinic. In a home setting, I'm in someone else's house, that's their locus of control and they're more likely to be honest with what's going on. With psychological support, which is often very intimate, you do need to quickly gain people's trust, and a hospital or clinic is the worst place to try and gain that trust. Often it's impossible, even with the greatest psychologists in our country. I think, yes, home visits are expensive, but you get more value for that time.

Dr Thomas-Unsworth told us about the development of resources and educating health professionals:

There's been talk about the need for a model, and I think that's one of the things Muscular Dystrophy UK's Mental Health Matters Steering Group has talked about: developing a best practice for psychology and psychological wellbeing more generally, but we're perhaps some way away from knowing what that is. How can we better construct services? There are projects around upskilling staff; there are projects around resource development, so that professionals can go to Muscular Dystrophy UK's website and access resources. There is also the beginning of a project to see if we can determine best practice for viewing neuromuscular conditions from a psychosocial point of view.

Dr Wright highlighted the difficulties of balancing travel time and the opportunities of technology:

It's incredibly difficult to have a service in Bristol and meet the needs of someone living at the tip of Cornwall. I think we do need to think about travel time. It's great to have people seen in their homes and to be empowered by that experience, but it also means you have a resource sitting in the car or on the train that could be better deployed over Skype. We need to look at maximum efficiency. We need a model, but we also need an efficient systemic change so that we're not training a ton of new psychologists without knowing how to utilise them. Specifically with regard to appointments, whether it's neuromuscular or any other issue, we're having children and families travel 150 miles to have a consultation, which could much more easily happen over Skype. It places an inappropriate burden and an inappropriate barrier around access to service.

Dr Thomas-Unsworth commented about how people with muscular dystrophy often learn about new technology through necessity:

My experience is that a lot of adults living with neuromuscular conditions, by necessity, have had to become very IT-savvy, as it is their primary means of communication with the world around them. My guess is that their tech skills are above other levels of the population because they've had to develop them. There is obviously a challenge in delivering psychological services through Skype because, while there is something gained through the accessibility, there is also something lost from the lack of interpersonal experience.

There was clear recognition that support for family members needed to be at the centre of plans to improve access to psychological support. Dr Hutchings commented:

It's really important to recognise the tension that occurs for family members who are looking after people with a long-term condition and simultaneously want them to become independent as much as they can while still wanting to look after them. Helping the parents as well as the young people through those milestones is really, really important.

Dr Thomas-Unsworth told us:

It might be gaining more traction but I think when you can offer psychological support to a parent or sibling, it's not just about addressing their mental health needs, but also how it supports them to support the person who has the condition. In my experience, it can start to inform a feedback loop where I can confer with parents, after gaining consent, to discuss these issues with the team that is supporting their child and better meet their care needs. My intervention then becomes not only improving their coping or capacity, but also then to feed back when they're having difficulties with different aspects of the service.

Prof Willis highlighted the importance of partnership-working in palliative medicine:

I would like every hospice in the country to have access to a specialist in palliative medicine. I want every patient with a neuromuscular disease, irrespective of diagnosis, to have access to someone who can give them advice. And I would also like hospitals to start working in partnership with hospices and charities, not just saying that hospices take over the role, but seriously working in partnership with hospitals to do this effectively. We've found that the crossover between the palliative care person and the psychologist has really helped patients to express where they wish to die. And this has prevented unnecessary hospital admissions, where people are dying in hospital when they don't want to [die there].

We were concerned that the set-up and resources within specialised commissioning did not lead to changes needed for improved service delivery.

Dr Merrison told us:

I'm a believer in specialised commissioning but I don't think commissioning, at the moment, has the right level of resources to be able to deliver on the details necessary and to enforce the kind of change that we need. Where you can take something that is a whole system benefit and genuinely deliver it; in practice that's really very difficult. It requires resources, but also a level of authority to be given to specialised commissioning across a wide range of different organisations, mainly the NHS trusts.

Third evidence session: NHS England perspective, 8 May 2018

- Professor David Clark, Professor of Experimental Psychology, University of Oxford
- Ursula James, IAPT Programme Manager, NHS England

Prof Clark and Ursula James provided useful evidence to explain how NHS England's Improving Access to Psychological Therapies (IAPT) programme could have a beneficial impact for people with long-term conditions, such as muscular dystrophy.

Prof Clark gave us some background to IAPT:

The problem is that up until 10 years ago...less than five percent of patients in England, with common mental health problems, were getting evidence-based psychological treatments. But the government started a programme called IAPT that aims, over time, to change that picture. It took as its starting point the idea that we just didn't have enough therapists to deliver these treatments.

So it's a training programme. We can only train at a certain rate but there's a commitment to get to 10,500 new therapists by 2021, and we're about 7,000 in. It was then deployed in specialist psychology services around the country, and there's now one in every CCG [Clinical Commissioning Group] around the country.

Prof Clark highlighted the focus on long-term conditions and the need for better integration of mental and physical healthcare services.

However, a lot of people with anxiety and depression in community have long-term physical health conditions including muscular dystrophy. We know that about 40 percent of people with anxiety or depression have a long-term condition (LTC), but only 20 percent of people in IAPT had a long-term condition. So this was unfair. The Five Year Forward View is to address this issue, to expand IAPT by 66 percent with at least two-thirds of that expansion focusing on people with LTCs. The aim of that was to achieve equity. Some progress has been made. The latest report shows we've now moved to 28 percent of people in IAPT as having a long-term condition, but we're at the start. It's not simply a matter of encouragement; it's ensuring the services are fit for those patients.

A key feature of LTC programmes is to co-locate long-term conditions and mental healthcare so patients can meet psychological needs and physical needs in the same place and ensure that mental and physical practitioners are working together. So that's been a key feature of the development of services to far.

Ursula James added:

I think we're hoping that this will start a sea change of thinking among physical health colleagues. What we put into the document when we were devising services for IAPT LTC was considering how local areas would develop an IAPT LTC service. What we really want is for whatever places and pathways that local areas are working on with IAPT practitioners, that physical health colleagues have some way of assessing and looking at somebody's mental health alongside physical health. Because I think you're right, I don't think it happens very often. I think physical health [practitioners] looks at physical health, but what we're trying to do is bring those two together. But it will take a little while because it is a culture change.

Prof Clark also referred to the cost savings in physical healthcare, which could be made by the provision of psychological support:

We also know if you give psychological interventions for depression, you save considerably on physical healthcare costs, so much [so] that it covers the psychological treatments. We've been collecting this type of data, and some of the initial reports are quite encouraging. For example, in Cambridge they're observing big reductions in cost to physical healthcare by implementing psychological services. We're hoping this demonstration of savings will make lawmakers pull together and balance the physical healthcare budget with the mental healthcare budget. For too long there's been absolute separation between the two.

Prof Clark spoke about the need to include muscular dystrophy in the data coding system and actively encouraged further dialogue to discuss how this could be achieved:

The question is where this takes us with muscular dystrophy; there's quite a long way to go. The first thing is that in the IAPT minimum data set, muscular dystrophy is not one of the codes. This is critical, because if we want to see whether the available services help people with muscular dystrophy, we need to code it separately and look at the outcomes. This is something that we can address and it's very timely, because the IAPT programme is about to update its data set.

We're expanding this flag to cover a range of specific conditions and we would like to include muscular dystrophy and would like your advice on how that should best be done. That's important, because with this unique data set that collects outcomes on everyone, we would be able to look to see if we're helping people with muscular dystrophy, and if not we can ask what we can do to improve interventions.

Prof Clark highlighted the increase in the use of technology to deliver psychological support:

Improving delivery, using technology, is a huge research area. Skype is one way of doing it, and a number of IAPT services use Skype to conduct therapy more conveniently so people don't have to travel. There's also work on Internet-delivered therapy, where rather than coming in to see a therapist you actually access an Internet programme, which covers key parts of psychological therapy.

The literature shows that you still get the best results if you have a therapist, but they attempt to support now with phone calls and texts. It seems that for the good programmes that do this, you can get a lot of savings for therapists' time. Which means that the NHS can stretch its resources. So this is an area of active development.

Prof Clark spoke about the self-referral option for accessing IAPT and encouraged patient feedback:

IAPT accepts self-referral. You don't need to go to a GP to be referred, and a large portion of people self-refer. This is based on data from a pilot project, which opened up a system for self-referral, and the Department of Health then assessed the data. There were several key findings. The first was that, to a lot of people's surprise, people who self-refer were as severe[ly affected] as people referred by a GP and tended to have had the problem longer. They'd been suffering in silence.

We also ask people to fill out patient assessment forms before they begin, and following treatment. That gives them a chance to say whether they thought their therapist was knowledgeable, attentive, helpful, and whether they benefited from the services. We would encourage muscular dystrophy patients that go through IAPT to fill out those surveys to have their voices heard at the national level. [The surveys are] anonymous, which is important, because how [patients] feel shouldn't be affected by feelings about the therapist themselves.

Ursula James highlighted a programme, which could be copied to support people with muscular dystrophy:

Sheffield's service was one of the first adopters of IAPT for long-term conditions. They had some more central funding from the NHS to develop this, and over the past two years, they had been training up people who worked in physical health pathways to do the PWP [Psychological Wellbeing Practitioners] for IAPT. So when they delivered their IAPT LTC, they had people in the pain clinic who'd already been trained as PWPs, and they stayed in the pain clinic but acted as part of the pathway to IAPT LTC. You can see how something similar might work for people with muscular dystrophy and how specialists could be used.

Appendix

First evidence session:

Patient perspective, 21 February 2018

- Sue Barnley, whose son Harry has Duchenne muscular dystrophy
- Louisa Hill, whose son Archie has Duchenne muscular dystrophy
- Steve Ledbrook, who has Becker muscular dystrophy
- Jaspal Mann, whose son Kirath has Duchenne muscular dystrophy
- Sarah Mitchell-Innes, who has congenital myotonic dystrophy
- Mathy Selvakumaran, who has congenital myopathy

Second evidence session:

Health professional perspective, 21 March 2018

- Dr Caroline Hutchings, Consultant in Rehabilitation Medicine
- Dr Andria Merrison, Consultant Neurologist
- Dr Jatin Pattni, Specialist Clinical Psychologist
- Dr Michael Rose, Consultant Neurologist
- Andrea Russell, Neuromuscular Care Advisor
- Dr Sadie Thomas-Unsworth, Specialist Clinical Psychologist
- Professor Derek Willis, Consultant in Palliative Medicine
- Dr Ingram Wright, Consultant Paediatric Neuropsychologist

Third evidence session:

NHS England perspective, 8 May 2018

- Professor David Clark, Professor of Experimental Psychology, University of Oxford
- Ursula James, IAPT Programme Manager, NHS England

Terms of reference

The terms of reference for the inquiry are:

“To determine the availability of psychological support at specialist and community level for children and adults with muscular dystrophy and related neuromuscular conditions.”

Written evidence and additional evidence

The cross-party groups on muscular dystrophy in the Scottish Parliament, Welsh Assembly and Northern Ireland Assembly have all held meetings, which have focused on psychological support. The summaries from these meetings have been useful reference points for the APPG for Muscular Dystrophy to consider when putting together the recommendations for this report.

We received written evidence submissions on the importance of access to psychological support from:

Valerie Banks	Anna Rogers
Samantha Cornelius-Light	Dr Michael Rose
Julia Coupe	Heather Ryan
Lizzie Deeble	Kieron Sales
Phil Ducker	Don Schlaiffer
Sally Dyos	Sue Schlaiffer
Prof Alan Emery	Magda Sereda
Phillippa Farrant	Shelley Simmonds
Suzanne Glover	Sara Smedley
Louise Halling	Ellen Snead
Paul Jorden	Lorraine Thompson
Sharon Kitcher	Holly Tiffen
Sharon Ledbrook	Sanjay Vaja
Pauline Platts	Karen Winn
Andrew Robertson	'Richard'

All Party Parliamentary Group for Muscular Dystrophy, *Access to specialist neuromuscular care: The Walton Report*, August 2009

All Party Parliamentary Group for Muscular Dystrophy, *Impact of NHS reforms on access to specialist neuromuscular care*, March 2015

All Party Group on Muscular Dystrophy meeting in the Northern Ireland Assembly, 26 March 2018

Cross Party Group on Muscular Dystrophy meeting at the National Assembly for Wales, 14 November 2017

Cross Party Group on Muscular Dystrophy meeting at the Scottish Parliament, 9 May 2018 (including Sheonad Macfarlane's presentation on *'The Forgotten Generation' – the need for psychological support.*)

SMA Support UK patient survey findings, 2018

SMA Support UK Additional Notes, May 2018

All Party Parliamentary Group for Muscular Dystrophy

Access to psychological support for
people with neuromuscular conditions

November 2018